

**AN INVESTIGATION INTO PARENTAL ATTITUDES ABOUT SEXUALITY AND
CHILDREN WITH INTELLECTUAL DISABILITIES**

By

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**AN INVESTIGATION INTO PARENTAL ATTITUDES ABOUT SEXUALITY AND
CHILDREN WITH INTELLECTUAL DISABILITIES**

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Acknowledgements:

This Capstone is the culmination of my formal post-graduate education. This effort calls on my experience from my Teacher Education, Special Education training and my Counselling Master's program. I genuinely feel that I am combining my areas of expertise and creating a useful document for myself and others.

I look forward to reflecting on this project in about a year and see if I have actually used anything in my practice. If I do not implement any of the practical recommendations I will be curious about why. Creating a document like this takes a lot of effort and time. However, once finished I know that this project will enrich my life significantly.

Thank you to all my instructors. Your expertise and experience was invaluable.

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ABSTRACT

People with intellectual disabilities (id) living in Canada traditionally experience unique challenges and roadblocks as they seek to explore their sexuality. Often, they have a difficult time forming and maintaining romantic relationships because of lack of opportunity or education. This paper investigates the following question: What are the attitudes and beliefs of parents of children with intellectual disabilities that have a negative influence on the capacity of their children to explore and develop sexual identities? In law and in society, it is generally accepted that people with intellectual disabilities deserve the same rights and freedoms as any other person. It is also clear that people with intellectual disabilities have sexual and romantic thoughts and feelings. However, marriage and child bearing for people with id is infrequent and unusual. Parental attitudes are one factor that determines the opportunities and experiences of people with id. It is these initial understandings that help me in the development of this study. First, I will be investigating the problem of attitudes through a study of current peer reviewed literature. Then, I will develop a qualitative research study designed to identify and classify attitudes of parents about the sexuality of their children with intellectual disabilities. In this paper, I will present and explain the following conclusions. Parents want their children to have meaningful relationships with others, but they fear the possibility of abuse towards their children. Furthermore, parents are concerned about the ability and appropriateness of their children having children. At the same time, parents also feel unprepared to offer sexual health guidance to their children with intellectual disabilities. These potentially harmful attitudes are based on fear and ignorance. The problem is exacerbated by feelings of isolation and overwhelming stress. As a result of these findings and their negative implications, I recommend continued tracking of

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parental attitudes in order to develop appropriate interventions and supports for parents and children. In addition, the tracking will help educational professionals to observe any general changes of attitude over time.

Key words: Sexuality, Intellectual Disability, Education

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Chapter 1

Introduction.

People with intellectual disabilities (id) have experienced great gains in freedom and support over the last several decades. Canada, as a nation, has moved from the practice of institutionalization to societal integration. The legal rights of people with intellectual disabilities have become more and more entrenched. For example, people with id are finding meaningful employment and have more opportunities for supported housing that more resembles family living rather than prison. The Canadian Education system has developed programs and supports for people with id. However, sexual rights and freedoms for all, have remained very controversial.

In this Chapter, I will present an outline of my efforts to become more familiar with the issue of parental attitudes about sexuality and children with intellectual disabilities. I will demonstrate the importance of this topic to educational professionals. Finally, I will propose one way that I can personally contribute to the field of scholarship through a qualitative study. This chapter will establish a tone of professional curiosity, empathy and passion.

Statement of the Problem

Sexual freedom for people with intellectual disabilities is a confusing and controversial topic. Canadian society continues to struggle with ways to help people with Intellectual Disabilities develop and express sexual identity in healthy and appropriate ways. The issue of sexual freedom and expression, including relationships and reproductive rights, has been a challenging arena for people living with and supporting people with intellectual disabilities.

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Children with intellectual disabilities experience unique and significant challenges in their attempt to engage in meaningful and satisfactory sexual exploration.

Parents experience fear and doubt about the ability of their children to make safe choices regarding romantic partners, to manage sexual urges or desires and make appropriate decisions about reproductive management. Furthermore, parents of children with id generally feel unprepared to provide appropriate sexual health education.

Parental attitudes and styles of communication about sex has an influence on the children they raise. Parents play a major role in guiding their children towards sexual maturity. Parents may have attitudes about sexuality that limit full sexual freedoms of their children with id.

Purpose of the Study

As an educational professional, my primary goal in this project is to provide practical and useful information to other educational professionals who support students with intellectual disabilities. Educational Assistants give intimate and personalized emotional and academic support. Special Education teachers develop curriculum and provide meaningful learning opportunities. Counselors help children with id understand and negotiate the complex social challenges they face in high school. I intend to make this document relevant to these people.

High school is a social environment in which young people with id face difficult and confusing choices. Professionals, either formally or informally, inevitably provide some sexual education to children with id. All stakeholders want to provide the best quality instruction and support possible. Best practice requires that professionals gather up-to-date and relevant information in order to make the best decisions. Part of this process includes communicating with the appropriate stake holders regarding any educational issue.

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Parents are always important stake holders in the educational system. More than most teachers, Special Education teachers work very closely with parents. One reason for this is that children with id need individualized educational planning. For these students, parents have unique insights and understandings about the needs of their children.

I hope that the educational professionals who read this study will be better informed about the typical fears and concerns parents have about the sexual development of their children with id. In Chapter 2, I will provide a Literature review exploring the potentially harmful attitudes parents have about the sexual development and rights of their children with id. In Chapter 3, I will propose a specific qualitative study seeking information from parents of children with id living in Surrey, B.C. and attending a Surrey public school. Using this information, I hope that professionals will be able to develop the most appropriate sexual health education possible.

Statement of Evaluation Questions

This study seeks to answer one central question: What are the attitudes and beliefs of parents of children with intellectual disabilities that have a negative influence on the capacity of their children to explore and develop sexual identities? This question can be dissected into several more specific questions. First, what are some problematic parental attitudes about the ability of their children to form and maintain relationships safely and avoid exploitation/abuse? Second, what are some problematic parental attitudes about the ability of their children to manage Family Planning issues? Third, what are some problematic parental attitudes about the ability of their children to understand and follow sexual norms of behavior? Fourth, what are some problematic parental attitudes and perceptions of their children's Sexual Identity? Finally,

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what are some problematic parental attitudes about their own ability and obligation to be a sexual educator?

Importance of the Study

I have worked as a Special Education teacher for over 15 years. Virtually every year, one or more students I work with have discipline problems due to inappropriate social-sexual behavior. I have seen many boys get in trouble for bothering girls at lunch. These boys are attracted to some girls and invade their personal space and make socially inappropriate declarations of feeling. These boys don't mean harm, but they do not know how to deal with their emotions. I have known several teenage girls with id become pregnant from non-disabled boys who have no desire to have a real relationship with them. Inevitably, the Special Education department is approached by administration to provide some sexual health education with the hope of avoiding these unfortunate incidents.

Considering how important sexual health education is for people with id, it may be surprising to know that in my years as a teacher, I have almost never had a conversation about sexual health with a parent of one of my students. Transitional planning for adulthood is almost always focused on employment and IEP meetings are usually about course selection and ways to support students academically. I don't know if parents are uncomfortable discussing these issues or they think that schools have no role in this arena of their child's life. I have to admit to feeling uncomfortable raising the issue of sexual health with parents because I do not wish to cause discomfort for parents and I don't wish to take on the huge task of offering sexual health education without having the appropriate training and supports.

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I believe that the best sexual health education programs are programs developed and delivered by parents and professionals together in a coordinated manner. Therefore, clear communication between parent and professional is crucial. This study is designed to provide information to professionals about parental attitudes. Hopefully, this information will facilitate meaningful communication between parents and professionals.

Furthermore, sexual health is a right for all individuals. When sexual identity and expression is denied to individuals with id and sexual health education and support is inadequate, a great harm is done. People with id have reduced quality of life with feelings of loneliness and isolation or they engage in inappropriate and potentially harmful sexual behaviors or they are more susceptible to sexual predators. It is my goal that this study be one contribution to open and productive discussions of sexuality. The benefits will be significant.

Scope of the Study:

One of the greatest challenges of this project is to narrow the topic down to a manageable size. Starting from a general interest in the sexual rights and freedoms of young people with id, I need to develop a focus. The first thing I will do is focus on attitudes towards sexuality and people with id. I will then chose to further focus on the attitudes of one segment of society. The three most interesting segments of the population to me are family caregivers, professional caregivers and people with intellectual disabilities. I have decided to focus on parents, because it is the group I am least familiar with. I hope to incorporate this information into my teaching practice in order to improve my craft.

From this point, I have chosen to focus on potentially harmful parental attitudes. Gathering data about these types of attitudes is useful for professionals wanting to offer sexual

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health education support to people with id. After this reflection, I was able to form a meaningful and significant question for investigation: What are the attitudes and beliefs of parents of children with intellectual disabilities that have a negative influence on the capacity of their children to explore and develop sexual identities?

Please be aware that this study does not try to quantify the prevalence of harmful attitudes, it simply tries to identify the most apparent harmful attitudes. I do not say what percentage of parents feel a certain way about things like sterilization, mainly because it is not possible to quantify such attitudes based on a survey of current Literature.

Also, please note that my focus is on attitudes of parents from North America. However, I fully acknowledge that attitudes most likely differ from region to region. This is the main reason why in Chapter 3 I propose a localized research study which will be most directly useful to professionals in Surrey and the greater Vancouver area and will have implications for others as well.

Summary

The problem that I have identified is that people with intellectual disabilities experience unique and significant barriers to sexual development and sexual expression. I will seek to determine the attitudes and beliefs that parents may have about sexual identity, expression and education that might be harmful to their children with id. I wish to provide information to professionals in order to facilitate meaningful communication between parents and professionals who support children with intellectual disabilities. This study is one contribution towards the recognition of rights and a recognition of the support needs of people with id in order to live meaningful and satisfying lives.

Outline of the Remainder of the Paper

In Chapter 2, I will delve deeply into the existing Literature about parental attitudes about the sexuality of children with id. This will be an academic exploration of peer reviewed studies. I will organize the Literature review based on specific themes of inquiry that can be found in my Statement of Evaluation Questions section.

In Chapter 3, I will propose and develop a qualitative study of attitudes about sexuality of parents with children with intellectual disabilities. This activity will be a phenomenological study that seeks to identify themes of concern as presented by parents in one-to-one interviews. The structure of this study will emerge from the deficits of the information gathered in Chapter 2.

In Chapter 4, I will summarize and synthesize my findings from Chapter 2 and 3. I will explain the significance of this Capstone activity and I will make several recommendations for educational professionals who support young people with intellectual disabilities.

Chapter 2

Introduction

In Chapter 2, I will review the relevant peer reviewed literature regarding parental attitudes about sexuality and their children with intellectual disabilities. The specific question I seek to explore is, “What are the attitudes and beliefs of parents of children with intellectual disabilities that have a negative influence on the capacity of their children to explore and develop sexual identities?” This will lead to a proposal to interview parents of children between the ages of 13-18 with mild intellectual disabilities who attend a public school in Surrey, BC. (Chapter 3).

Based on my exploration of peer reviewed literature, I have been able to organize much of the information and data into the following thematic topics. First, I will explore parental attitudes about the ability of their children with id to form and maintain safe relationships and avoid abuse or exploitation. I am interested in exploring the following questions. Do parents think their children are able to form and maintain long term romantic relationships? For example, do parents support the idea of marriage for their children? Do parents feel that their children are at greater risk for sexual exploitation and abuse than the general population? Second, I will explore parental attitudes about the ability of their children to manage Family Planning issues. Do parents think their children should have the right to have and raise children? Do parents support forced or coerced sterilization for their male or female children? Third, I will explore parental attitudes about the ability of their children to understand and follow sexual norms of behavior. Do parents believe their children are able to distinguish between private and public behaviors? Do children believe their children can control sexual impulses? Do parents believe their children are capable of learning and personalizing basic facts related to sexuality? Fourth, I will explore parental attitudes and perceptions of their children’s sexual identity. Do

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parents see their children as asexual? Are parents open to homosexual/bisexual behaviors in their children? Finally, I will explore parental attitudes about their own ability and obligation to be a sexual educator for their children? Do parents feel able to provide adequate sexual education to their children? Do parents feel that sex education is useful for their children? Do parents support the right to sexual education?

To conclude the literature review, I will briefly address the issue of parental attitudes from various other countries around the world. An exploration into the international arena will give insight into the cultural origins of these attitudes towards sexuality. Considering the multicultural nature of Canada and the high level of immigrants in Canada, understanding the origins of these attitudes may be very helpful to researchers and educational professionals who wish to develop meaningful interventions and support systems in place.

Definition of Terms

To ensure clarity of understanding, I will provide to the reader context and definition for several key and important concepts.

Terms and Concepts:

- a. Attitudes: For the purpose of this Capstone project, the definition of attitude will be relatively broad. Also, as this project is not really about finding a scholarly definition of attitude, a broad and general definition seems appropriate. Therefore, I will use the term, “attitude” to mean the mental process of evaluating and judging a person, event or idea. In this case, how do parents of children with id evaluate and judge their children’s abilities tendencies, and rights? Also, how do parents evaluate their own ability and obligation to be sexual educators? Attitudes may be pre-cognitive or the result of extensive observation and

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exploration. Attitudes must influence one's behavior. As a result, the study of parental attitudes is important because it may help us understand the actions of parents.

- b. **Intellectual Disability:** For brevity I will frequently refer to intellectual disabilities as "id". An intellectual disability refers to a deficiency in the mental or intellectual capacity of an individual as based on current psychological procedures and tests. Specifically, the characteristic of an intellectual disability is an IQ less than 70. Intellectual disabilities also require a significant impairment in adaptive functioning. This means a person with an id will have difficulty in functioning in several domains including conceptual skills, social skills and practical, daily living skills. Intellectual disabilities can be mild, moderate or severe in nature. This study does not distinguish parental attitudes based on the severity of intellectual disability, mostly because there is a dearth of literature that identifies the severity of disability as a relevant factor. However, it seems likely that there would be significant differences in attitude based on the severity of disability. Nevertheless, the literature under review generally describes people with id as mostly having a mild to moderate intellectual disability, but does not actually specify differences within the realm of intellectual disability. Parental attitudes of children with severe intellectual disabilities are not specifically included in this literature review. This has been a challenge for me in this project which I will explore in more depth later.
- c. **Parent/ Family Caregiver:** The parents under study in this project are primary caregivers of children with intellectual disabilities. Parents do not have to be biologically connected to the individual child with id. Unless otherwise specified, when I refer to parents, this can mean any combination of caregivers. For example, parents might be biological mother and father, or single mother or single father, etc.

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- d. **Sexual rights:** A right is a moral or legal entitlement to obtain something or to act in a certain way. Sexual rights refer to one's moral and legal status in regards to sexual expression and identity. If people with id have different or less rights than others, it would be seen in legal documents like the Canadian Charter of Rights. In addition, sexual rights may also be found in documents like The Universal Declaration of Human Rights by the United Nations. Although legal status is an evolving thing, the general principles of non-discrimination and equal rights for all provides us with a baseline for understanding legal rights.
- e. **Sexual Development/ Growth:** Theories of development abound from Freud to Piaget to Vygotsky. For the purposes of this project, I will not delineate between the various theories. The real issue is how much is known about the growth from sexual immaturity to sexual maturity in terms of behavior and identity. The question some may have is, "Is it possible for people with id to develop into sexual maturity?" If it is possible, how might it be similar or different from the general population? If sexual maturation is different, to what extent does it justify limiting freedom of people with id? These are questions that society and parents specifically have to wrestle with.
- f. **Sexual Education:** Sexual Education may be formal or informal. The ideal purpose of Sexual Education is to prepare individuals to understand sexual impulses and make safe and healthy choices about sexual expression. The providers of sexual health education of children has changed and evolved. However, typical providers of sexual information in the past has been parents, school staff, peers, the media or religious instructors. The quality of sexual health education has varied widely. Without dismissing the importance of other sources of sexual health education, it is clear that parents can have a very influential role in

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educating their children. Therefore, it is valuable to know about parental attitudes about their own role in this process of sexual preparation.

- g. **Family Planning:** Family planning refers to the ability of a person to make rational and purposeful choices about marriage, having and raising children or the use of birth control. All people, whether they are intellectually disabled or not, have variable skill sets when it comes to Family Planning. Family planning is not always fully intentional. However, as will be shown, parents often fear the decision making ability of their children with id. Does this attitude reveal a bias against people with id or is it reasonable to think that people with id are not able to live with the consequences of their choices and people of average intelligence are able?

Historical Background:

The historical evolution of rights and freedoms for people with intellectual disabilities in Canada has been slow but significant. Overall, the directional movement has been towards greater freedom, higher inclusion and more support for people with id. However, families with children with id continue to carry the highest burden of care. Nevertheless, governments have slowly provided some financial support for families struggling with the unique challenges of raising children with id. The arena of sexual freedom for people with id has its own special controversies. Specifically, sexuality often is a taboo topic and people feel uncomfortable discussing sexuality.

The issue of sexual freedom for people with id has been affected by ignorance and prejudice as well as paternalism and fear. Common misconceptions about people with id is that they are asexual in nature. In other words, children do not develop sexual feelings or experience

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sexual urges. On the other hand, a common myth is that people with id are prone to sexual deviance and are unsafe in society because they are over sexed and unable to control these urges. The reality is that both of these perceptions are false or at least misguided.

These perceptions have led to irrational fear in society. These misconceptions have led many in society to suggest many harmful policies that limit the sexual rights and expressions of people with id. Some of the significant limitations imposed have been forced or coerced sterilization. Of course, fear of sexual deviance has supported the movement towards greater control and institutionalization. Furthermore, these misconceptions essentially support a system of paternalism towards people with id. At best, this means a system of care that unnecessarily limits the rights and freedoms of people with id with the perception that these limitations are for their own good. At worst, this means a system of carelessness that cruelly disposes of a perceived nuisance in institutions or other highly restrictive environments.

Purpose and Source of Literature Review

The problem I have identified is that people with intellectual disabilities do not, generally speaking, enjoy the same level of freedom to explore sexual identity and preferences as the general population. Furthermore, I hypothesize that parents of children with id may hold attitudes that limit the sexual freedom and expression of their children. The question being explored in this literature review is, “what are the attitudes and beliefs of parents of children with intellectual disabilities that have a negative influence on the capacity of their children to explore and develop sexual identities?” As extensively as possible, I intend to acquaint the reader with the most relevant and up to date peer reviewed literature that either directly or indirectly explores the question identified. I will share my knowledge of the research related to this question.

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Finally, I will provide recommendations about further research that may be done to increase understandings related to the question and problem.

Literature Review:

As stated in the introduction to Chapter 2, the Literature review is structured and organized into several thematic topics. Under each thematic topic, I give a general overview of the topic and then share the information from the Literature.

Parental Attitudes: Forming and Maintaining Safe, Non-Abusive Relationships

In this section, I will explore parental attitudes about the ability of their children with id to form and maintain safe relationships and avoid abuse or exploitation. Do parents think their children are able to form and maintain long term romantic relationships? For example, do parents support the idea of marriage for their children? Do parents feel that their children are at greater risk for sexual exploitation and abuse than the general population?

It is easy to understand why a parent may feel that their children are at great risk for being exploited or abused within romantic relationships. Their children are often placed in vulnerable positions with professional support staff as well as the general population. It would be natural for a parent to wonder if their child is able to safely choose a mate or romantic partner.

Parents who believe that their child with id is at great risk of being a victim of sexual abuse have some evidence to support their fears. Horner-Johnson and Drum (2006) reviewed studies published from 1996-2005 to determine the rate of maltreatment of individuals with intellectual disabilities. Maltreatment is a broad term that includes, but is not limited to, sexual abuse. The results of the study found that there is very little literature on this subject but the available literature, “suggest(s) that maltreatment is more prevalent for people with id than for

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people with no disabilities and may be higher for people with ID than for people with certain other disabilities.” (Horner-Johnson, 2006, p. 57) This not very specific, but does raise concerns and suggests further research in this area is needed.

Even if the evidence for high risk of sexual abuse is unfounded, the literature clearly shows that many parents have strong fears of sexual abuse for their children. Michelle Ballan summarizes this issue very clearly. “Some parents... fear that their children will be unable to express their sexual impulses appropriately, will produce children... and will be targets of sexual abuse or exploitation.” (Ballan, 2001 p. 14) This fear, “often results in overprotection” and parents, “may suppress their children’s sexuality.” (Ballan, 2001, p. 14)

Other studies exist that explore parental fear of sexual abuse of their children with id. Pownall, Jahoda and Hastings conducted an extensive study that compared attitudes and behaviors of mothers with children with id to mothers with children without id. The authors developed questionnaires and interview questions about sexuality and sexual education. There were 30 mothers with children with id and 30 mothers with children without id. This study will come up in several other sections of this literature review as well. The overall finding was that mothers of children with id held more cautious attitudes in general. Specifically, mothers with children with id expressed greater concern about sexual vulnerability. (Pownall, Jahoda, & Hastings, 2012, p. 140)

Although parents are aware that children with id have the right to have sexual experiences, it is this conservativeness and fear of sexual exploitation that causes some parents to be highly restrictive of their children’s sexual experiences (Pownall et al., 2012, p. 141). According to another article about Mother’s experiences, Ankeny, Wilkins and Spain found that, “In particular, mothers struggled to accept the desires of their daughters to date and marry and

grappled with internal conflicts over wanting their daughters to live like other young adults.”

(2009, p. 32)

Overall, the Literature seems to support the idea that many parents experience significant fear for their children’s safety when it comes to forming relationships. In particular, parents fear the potential for abuse. As a result, parents may exert significant restrictions on their children’s freedoms. Obviously, these safety restrictions would inevitably lead to reduced opportunities for people with id to meet potential mates and develop relationships that could lead to marriage. After all, a certain amount of privacy is crucial for the development of healthy romantic relationships.

Parental Attitudes: The ability of children to Manage Family Planning

In this section, I will explore parental attitudes about the ability of their children to manage Family Planning issues. Do parents think their children should have the right to have and raise children? Do parents support forced or coerced sterilization for their male or female children?

The issue of forced sterilization is a very controversial subject with a disturbing history. Sterilization brings up thoughts of eugenics and the horrors of Nazi Germany. However, sterilization is still an issue that parents have to wrestle with in raising their children with id. Aunos and Feldman studied existing literature on the issue of attitudes about sterilization and parenting rights of persons with intellectual disabilities (2002). The literature goes back from the 1970’s to the time of publication. Although not specifically about parental attitudes, this research gives some useful information about parental attitudes. This study is also useful because it is Canadian. Aunos found that up to 80 % of service workers and parents were in

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favor of sterilization (2002, p. 288). Unfortunately, this research goes back to the 1970's and is so outdated as to have little or no relevance to now. My search for relevant and up to date literature left me essentially empty handed. This may be because the issue of sterilization is so outdated as to be irrelevant. On the other hand, this lack of available literature on sterilization also points to a need for further research.

Conod and Sevais came to an interesting conclusion about sterilization. "Indeed, because of suspected poor medical compliance and/or vulnerability to sexual assault, persons with intellectual disabilities are often considered candidates for surgical sterilization. Parents and caregivers have expressed a strong preference for these methods, and there is a high satisfaction rate when they are performed." (Conod & Servais, 2008, p. 230) However, the data supporting this conclusion also seems to be very old coming from studies from the 1970's or 1980's.

There are family planning issues separate from sterilization that are relevant to this project. For example do parents support the right of people with id to raise and have children? The literature suggests that parents, as well as other professional caregivers are worried about and wish to avoid pregnancy (Aunos, 2002). There are at least two possible reasons for this. First, parents may think that their children would be incapable of raising children and, second, parents may fear that the parents may genetically pass on the intellectual disability.

Brown and Pirtle published a study about beliefs of professional and family caregivers about the sexuality of individuals with intellectual disabilities (2008). Again, although this study was not exclusively about parental attitudes, this study provides rich information about parental attitudes. In this study, Brown and Pirtle were able to identify 4 belief systems that professional and family caregivers have. The four systems are advocates (strong supporters of human rights for the individual with intellectual disabilities), supporters (ardent supporter of sex education for

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the individual with intellectual disabilities), regulators (supporter of extensive birth control measures), and humanists (the strongest supporters of human rights for the individual with intellectual disabilities) (59).

I will refer to this study in other parts of this project, but here I will summarize how members of each belief system feel about family planning issues. Participants were given statements and asked to rate the level to which they agree or disagree. The range of responses were from -4 to +4. Advocates agree (+3 or higher) with statements like the following: It is unfair to prevent individuals with intellectual disabilities from having children (Brown & Pirtle, 2008, p. 67). Advocates disagree (-3 or lower) with statements like: The individual with intellectual disabilities should be taught about sex and then sterilized to prevent pregnancy (2008, p. 67). Supporters agree with the following statement: Birth control methods should be stressed in sex education for individuals with intellectual disabilities (2008, p. 68). Supporters disagree with statements like: Sterilization should be used because it alleviates problems for the individual with intellectual disabilities and their parents (2008, p. 68). Regulators agree with statements like: Birth control methods should be stressed in sex education for individuals with intellectual disabilities (2008, p. 69). Regulators disagree with the statement: Discussion of AIDS and other sexually transmitted diseases will only serve to scare individuals with intellectual disabilities (2008, p. 69). Humanists agree with the statement: Birth control methods should be stressed in sex education for individuals with intellectual disabilities (2008, p. 70). Humanists disagree with the statement: As a tax-paying citizen I believe individuals with intellectual disabilities should be sterilized to prevent them from having children (2008, p. 70).

The fact that all systems of belief demonstrate attitudes of strong and meaningful support for people with id and family planning is encouraging. It suggests that parents, who must fall

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into one of those systems of belief, actually oppose sterilization and support other forms of birth control through sexual education. Those people in the advocate category actually support the notion that people with id should not be prevented from having children against their own will. These findings challenge my hypothesis that parents hold negative attitudes about family planning for those with id.

Parental Attitudes: The ability of children to understand and follow Sexual Norms

I will explore parental attitudes about the ability of their children to understand and follow sexual norms of behavior. Do parents believe their children are able to distinguish between private and public behaviors? Do children believe their children can control sexual impulses? Do parents believe their children are capable of learning and personalizing basic facts related to sexuality?

If parents feel that their child is unable to distinguish between private and public behaviors, it might cause parents to suppress sexual expression and knowledge, in order to mitigate the possibility of private actions in public spaces. If parents feel that their child is unable to fully control sexual urges, they may choose to limit normal socialization opportunities for their children.

The literature does give some insight into parental attitudes about these issues. To begin, one study from 2012 about parental perspectives of communication about sexuality in families of children with autism spectrum disorders, Michelle Ballan found that many parents feared that non-sexual behaviors would be misperceived as being sexual in nature by the public (M. S. Ballan, 2012, p. 679). In other words, children may not be aware of norms regarding personal space. This is an interesting observation, because it shows that non-sexual behaviors can still

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have an impact on the sexual life of children with disabilities. Unfortunately, this study was strictly about children with autism and not necessarily intellectual disabilities. However, the co-morbidity of id with autism is relatively high between 25-70 % (Dawson, Mottron & Gernsbacher, 2008). We can safely assume that some of the children with autism in this study also had intellectual disabilities.

In a 2001 paper about parents as sexuality educators, Michelle Ballan claims that, “Some parents of children with developmental disabilities also fear that their children will be unable to express their sexual impulses appropriately. To alleviate fears and anxiety, parents may suppress their children’s sexuality.” (M. Ballan, 2001, p. 14) Although this is an important statement, Ballan does not quantify what “some parents” means. This quantification may be helpful in determining systemic interventions. Perhaps more specifically and emphatically, Ballan also states that there is, “no empirical data to support the belief that sexuality education will result in experimentation...” (2001, p. 15) This contradicts the attitude that some parents have about the dangers of giving people with id sexual information.

In another study about caregiver perceptions of sexual behavior the author found that, among other things, public displays of affect by people with id were perceived as being potentially inappropriate (Swango-Wilson, 2008, p. 80). This finding is important because it reveals that some caregivers perceive the same action from a person with id and a person without id as significantly different in appropriateness. The issue of social norms is turned on its head. Caregivers do not expect people with id to behave within social norms, and when they do, it causes discomfort in the caregiver.

Pownall’s 2012 study about mother’s attitudes found that parents of children with id are more likely to believe that discussing sex would encourage sexual behavior or promote

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inappropriate behavior (p. 141). This perception goes to a core belief that giving knowledge to people with id would lead to bad results. This reveals a fundamental bias that people with id are not capable of making wise choices about private actions in public spaces.

Brown and Pirtle's study, who identified the 4 belief systems of advocates, supporter, regulator and humanist, present's a different perspective. All four groups strongly support a statement like: "Moral considerations about sexual behavior should be discussed with the individual with intellectual disabilities." (2008, p. 67) Another supported statement is: "Everyone who can understand sex education should be instructed" (p. 67) These statements are more positive and indicate that people with id can be taught to follow sexual norms.

From Ireland, D.S. Evans conducted a study comparing attitudes of staff and family caregivers about sexuality and relationships for people with intellectual disability. The general finding was that family care givers are less likely to discuss sexual issues with their children than paid staff (Evans, McGuire, Healy, & Carley, 2009, p. 913). In this study, participants were asked to share their thoughts about 3 scenarios. One scenario involved two individuals with id who engage in intimate acts in a public park. Family caregivers were less likely to support open discussion of the issue with the individuals involved and, furthermore, "Family carers were more likely to be critical of factors that allowed the scenario to occur, and suggested preventative, rather than educational interventions to ensure that the event does not recur." (Evans et al., 2009, p. 918-919) This response to inappropriate public displays of affection reveal a strong discomfort with the autonomy of individuals with id and a preference for the controlling of individuals with id.

Parental Attitudes: Sexual Identity

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In this section, I will explore parental attitudes and perceptions of their children's sexual identity. Do parents see their children as asexual? Are parents open to homosexual/bisexual behaviors in their children?

Sexual identity relates to how one thinks about themselves in terms of gender identity, sexual orientation and romantic orientation. Sexual identity is the result of self-reflection and can be an extremely complex and nuanced construction. Therefore, it is reasonable to wonder if intellectual disability is an impediment to the process of constructing sexual identity. However, sexual identity does not have to be painstakingly constructed. Rather, sexual identity may be more intuitive, something someone just senses within themselves. In this way, we can see that intellectual impairment need not preclude the possibility of sexual identity.

Admittedly, the reason why I chose this theme is based more on speculation rather than hard evidence of parental attitudes negating sexual identity of their child with id. Although there is literature about the difficulties of people with id struggling with sexual identity and orientation, I could find no specific study about how parents reject their child's exploration of sexual identity and orientation. Therefore, this section must remain sparse. The greatest evidence of parental attitudes of sexual orientation is not from North America, but rather from Northern Europe including the United Kingdom as well as a contribution from Australia. We are left to speculate about the connection to Canada in general.

From the UK, Abbott and Burns, conducted a study about staff views on supporting gay, lesbian and bisexual people with intellectual disabilities in 2007. In this qualitative study there are some glimpses about parental opinions about sexual orientation. Based on interviews with 9 women and 11 men with id identifying as lesbian, gay or bisexual, individuals with id are very reluctant to come out to their families (Abbott & Howarth, 2007). When they do come out, the

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result is not as supportive as hoped. One woman who told her mother she is gay was greeted with, “You’re gay? You don’t know what it is to be gay. You don’t understand. You’re not gay, you don’t know what you are talking about, you’re just going through a phase.” (Abbott & Howarth, 2007, p. 32) This quote shows that this mother does not believe her daughter is capable of even understanding homosexuality. Jim, a gay man, got an even more disturbing response from his father, “It’s sick... It’s sick that men want to...” (Abbott & Howarth, 2007 p. 32) This parental response may not be significantly different from what non-intellectually disabled individuals would receive, but it shows that people with id certainly have trouble with parental attitudes against non-traditional sexual orientations.

From Australia, I found a 2011 article by Noonan and Gomez which is constructed to present the complexity of issues which prevent LGBT people with intellectual disability from living full lives and having opportunities for sexual expression. The authors point out a general attitude and belief that if people with intellectual disabilities have sexual identity, they are heterosexual. (Noonan & Gomez, 2011 p. 176) The authors further state that people with intellectual disabilities often grow up in restrictive environments whether it be supported accommodations or with families. (Noonan & Gomez, 2011 p. 176) The obvious implication is that people with id will face negative responses to expressing non-traditional sexual orientations.

From Sweden comes a qualitative study with the purpose of identifying, describing and understanding the opportunities and hindrances for young people with intellectual disabilities in expressing a variety of sexual expressions, such as homosexuality and bisexuality (Löfgren-Mårtenson, 2009). Through interviews, the author sought to find out the attitudes of parents and staff members concerning homosexuality and bisexuality and young people with id. The result was that, “not a single parent reported that their son or daughter was homosexual or had ever

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expressed a desire for same-sex activity (Löfgren-Mårtenson, 2009 p. 23). Only 11 parents were interviewed, so the results are certainly limited. However, this result emphasizes the invisibility of people with id having non-traditional sexual orientations.

Parental Attitudes: Parents as sexual health educators

I will explore parental attitudes about their own ability and obligation to be a sexual educator for their children? Do parents feel able to provide adequate sexual education to their children? Do parents feel that sex education is useful for their children? Do parents support the right to sexual education?

Current literature supports sexual health education for people with id. According to Michelle Ballan, “One factor increasingly associated with reduced or delayed sexual behavior is communication between parents and their children about sexual health.” (M. S. Ballan, 2012, p. 677) Knowledge has positive outcomes in terms of potentially dangerous sexual activities. Ballan, in another study, points out that no empirical data shows that sexual health education leads to experimentation in people with id. (M. Ballan, 2001, p. 15) Natalie Gougeon, in her article about sexuality education for students with id, makes the critical comment that current sexual health curriculum, as it is currently being presented, actually promotes sexual incompetence (Gougeon, 2009, p. 277). Rather than being a reason to stop sexual health education, this claim is really a call to making sexual health programs better.

If sexual health education is a positive and useful thing, it must be presented by professionals and parents who feel that sexual health education is purposeful. Unfortunately, much of the literature shows that a significant amount of parents feel that sexual education will have a negative or no impact on children with id. For example, one parent felt reluctant to talk

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about sex with his 12 year old son with id because, he felt it would be irrelevant to his life and would distract him from other things in his life. (Ballan, 2012, p. 680) Another example of parental feelings against sexual health education comes from the study of mother's attitudes about sexuality by Pownall. In this study, Pownall found that mothers discussed sexual health issues with less detail, at a later age and on fewer topics than mothers with children without intellectual disabilities (Pownall et al., 2012, p. 147, 149). I would interpret this phenomenon as being motivated by feelings of inadequacy and incapacity on the mother's part. The fact that mothers also were less inclined to discuss abstinence and sexually transmitted diseases suggests that these mothers do not think their children are likely to engage in sexual behaviors with others (Pownall et al., 2012, p. 148). It also supports the notion that children with id are not capable of understanding detailed information about sexuality in the same way as non-intellectually disabled children. Pownall supposes that many mothers actually feel that sexual health education may provoke unnecessary anxiety within their children (Pownall et al., 2012, p. 151).

There are several examples in the Literature that show, even if parents want to be involved in sexual health education with their child, they feel inadequate to the task. Brown and Pirtle claim that parents do not feel prepared in discussions of sexual health (Brown & Pirtle, 2008). When they do engage in discussions, they tend to focus more on biological factors, rather than social factors. The fact that social issues are much more nuanced and complicated shows that parents may feel unprepared to deal with complicated issues of sexuality. Pownall points out that mothers of young people with ID reported having fewer sources of informal support. (Pownall et al., 2012, p. 150)

Given that many parents feel sex education is unnecessary or harmful and they feel unable to provide adequate guidance, there is a clear need for education of parents to help them

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recognize and accept the emotional and sexual needs of people with id (McCabe & Ph, 1999, p. 159). Furthermore, the development of sexual health programs should involve parents, among other stake holders. (Gougeon, 2009, p. 283) In order to involve parents, it is crucial to that parents come to feel that sexual health education is important and that they have an important role in its delivery. This conclusion is one of several practical implications of this capstone project. After all, it is pointless to simply point out deficits or problematic beliefs of parents without working towards meaningful solutions and support mechanisms for parents.

Multicultural Issues

This capstone project has been mostly an exploration of parental attitudes of parents in Canada. It has been impossible to distinguish between different regions of Canada or attitudes of people from different cultural backgrounds. It is almost certain that significant differences exist, however. This is one reason why, in Chapter 3, I will propose a qualitative, interview based, study that focusses on one small region of Canada: Surrey, B.C. I feel that this kind of study will be more useful to professionals who hope to develop appropriate interventions.

One thing the existing literature can do is give a glimpse into attitudes from other countries. I was able to find studies based out various countries in Europe, Australia and India. As multicultural perspectives is not the focus of this project, I will not delve too deeply into this arena, but I will share some key observations based on the literature.

From Australia, Cuskelly and Bryde assessed attitudes in parents and care givers about people with intellectual disabilities (Cuskelly, Bryde, & Centre, 2004). It was found that parents are more conservative than staff care givers. By conservative, the authors refer to attitudes

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supporting restriction of sexual behaviors. For example, parents were less positive about people with id having children.

Another key observation the authors point out is that attitudes are affected by age; the older the person, the more conservative the attitude.

From Ireland, D.S. Evans came to similar conclusions. Parents, in this questionnaire survey, were less open to discussing issues of sexuality with people with id and these attitudinal differences are affected by the age of the care giver (Evans et al., 2009)

In a fascinating study from Sweden, the author sought to find information about the hindrances and opportunities young people with id have in expression of sexuality. The study was done through observations at organized dances for people with id and interviews of parents. One key conclusion was that parents feel responsible for their children's sexuality and act as disciplinarians toward their children (Löfgren-Mårtenson, 2004).

Without evidence, many people would assume that India is a country in which parents may have the most negative of attitudes, especially compared to contemporary Canada.

However, two authors have tried to counter this narrative by identifying positive perceptions in parents of children with id. The authors begin with a very eloquent acknowledgement of the negative narrative:

Existing studies reveal that very often the parents have a negative attitude towards their child with disabilities. The parents are plagued with feelings of pessimism, hostility, and shame. Denial, projection of blame, guilt, grief, withdrawal, rejection, and acceptance are the usual parental reactions. Some parents also experience helplessness, feelings of inadequacy, anger, shock and guilt whereas others go through periods of disbelief, depression, and self-blame. (Gupta & Singhal, 2004, p. 23)

The authors seem to contradict these attitudes by generating a very interesting thesis. The authors found some evidence of positive feelings in parents. One study showed that father's feel stress and negativity, but also strong positive feelings and claims of personal growth. The

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authors add an interesting interpretation for the existence of positive feelings. Specifically, positive feelings serve as a coping mechanism for parents. “Existing individual and family focused theories suggest that positive perceptions play a central role in the coping process.” (Gupta & Singhal, 2004, p. 25) This is an interesting perspective, because this capstone project has shown that certain parental attitudes have negative impacts on people with id and other parental attitudes can have positive impacts on people with id. Gupta turns this concept around and shows that attitudes also have positive impacts on the parents themselves. This actually reinforces the powerful impacts of attitudes on parents and children.

Summary

This capstone identifies the problem that people with intellectual disabilities experience challenges and roadblocks in the process of sexual exploration and identification. People with intellectual disabilities have a hard time forming and maintaining romantic relationships. The Question under investigation is: What are the attitudes and beliefs of parents of children with intellectual disabilities that have a negative influence on the capacity of their children to explore and develop sexual identities?

The literature confirms that the problem really exists and has offered some insight into the question under investigation. It has been difficult to quantify the impact of parental attitudes and it has been difficult to create a monolithic image of a typical parent. However, the literature has allowed me to identify key detrimental parental attitudes, beliefs and feelings about their child’s sexuality. I have shown that many parents fear sexual exploitation and abuse. As a result, parents may become overly protective of their children. I have discovered that many parents are deeply concerned about the right of people with id to have children. As a result,

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forced contraception is a risk. I have identified that parents are afraid that their children will engage in inappropriate public behaviors. This can lead parents to feel reticent about providing knowledge of their children for fear that they will be encouraged to participate in inappropriate behaviors. I have exposed anti-homosexuality in some parents which inevitably leads to repression of sexual expression of people with id. Finally, I have revealed attitudes of antipathy and/or incapacity towards providing sexual health education for people with id. These attitudes inevitably lead to poor or non-existent sexual health education. The lack of properly developed sexual health education is demonstrably harmful to people with id.

There are many remaining questions that I have after this literature review. There are things I would like clarified. For example, I am very interested in finding more information about cultural differences within Canada and I also want to know more about differences related to the gender of parents and the gender of the children. Certain claims that I have made are open to different interpretation as well. For example, the anti-homosexual attitudes I have identified may have little to do with intellectual disabilities, but reflect a generalized prejudice. Furthermore, I am not claiming to have provided a comprehensive exploration of the topic of parental attitudes. There is so much room for further study. In Chapter 3, I will offer one possible contribution to this field of study.

Chapter 3

Introduction

Parental attitudes about the sexual development of their children with intellectual disabilities have the potential to limit or negatively impact the development of their children into fully realized sexual beings. As was demonstrated in Chapter 2, this topic clearly requires more research to come to a more precise thesis. At this time, the most specific claim I can make is that negative attitudes are based on fear and ignorance but not generally based on lack of care. My research proposal is an activity that may provide more practical insight for educators in the city of Surrey and throughout the province of British Columbia.

Purpose

To obtain “first person perspectives” about parental attitudes regarding the sexual development/ education of teenagers (13-18) with mild intellectual disabilities who attend Special Education programs in Surrey public schools. Such perspectives will inform the development of sexual health education/ interventions for school based staff working with students with intellectual disabilities.

As many authors have already acknowledged, any effective sexual health program, does require the meaningful input and coordinated participation of all stake holders. As young people have to spend much of their social time at school, it makes sense that educators will, inevitably, have to provide some guidance to the children in order to ensure the greatest chance for healthy sexual development. If this guidance is informed by the attitudes and perceptions of parents, such guidance has a better chance of being effective,

Methodology

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I propose a qualitative, interview-based, research study. The interviews would take the form of an in-depth one-on-one interview. Extraction of themes through phenomenological approaches. Analysis of data requires the identification of the essential experiences of raising a child with id as they enter into the process of sexual maturation. Through an identification of common essential experiences, an understanding of the origin and justification of various attitudes held by parents will emerge. For example, I might be able to find common origins for fear of sexual abuse or exploitation.

Initially, parents would be asked to share their beliefs and experiences with dealing with the sexual development of their children. The question might be framed like this: When you think about your child growing into adulthood, what thoughts and feelings do have regarding his/her sexual development and experience? The question is neutral and does not necessarily elicit negative responses. Participant responses would guide the progression of the interview.

The interview would be open ended and free from a specific agenda. However, there would be some guiding questions for the interviewer to refer when conducting the interview. There are three key guiding questions. First, what are your hopes for your child regarding romantic relationships? Second, what are your feelings about the possibility of your child having children of their own? Finally, could you describe the type of sexual health education that would be most useful to your child? These questions, should reveal attitudes about a broad range of topics.

Before the interview begins, participants will be asked to fill out a form asking for certain demographic information. The interview process will consist of one 60 minute interview with a follow up interview if deemed necessary by the researcher. The time frame for the interview can be flexible. Interviews will be audio recorded and data will stored in a sufficiently protected

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space. The protected space will be in accordance with ethic board requirements. Information will be kept in a locked filing cabinet and electronic information will be saved onto a hard drive and stored in the locked cabinet. Labels and names will be coded to ensure that no one other than the researcher will be able to breach the privacy of the participants.

After the author has organized the data into themes of commonality, the author will share these findings with the parents to ensure that the author's interpretation is consistent with the parent's feelings. The data will be organized by the author with interpretations and submitted for peer review. The peer feedback will be used to create an article that is academic in nature.

Participants.

I propose to interview the parents of 10 different families. Interviews would be with parents with children who have a Mild Intellectual Disability. I would want to limit my interviews to parents of children with mild intellectual disabilities rather than moderate to severe disabilities. I suspect the attitude differences would be great enough to justify a second study of that particular group. In order to ensure cultural diversity, I would send out translated versions of my study proposal so that as many people as possible would read and understand the research.

Ethical considerations.

I will do everything I can to ensure that the interviews and data gathered does not violate the privacy of children with id. As the interviewer, I would talk to parents from unidentified schools and use pseudonyms. These procedures would be consistent with the guidelines set out by the research ethics board.

To what extent is the permission of the children needed in order to proceed with research interviews? The anonymous nature of the interview should alleviate this concern. However, it

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should be acknowledged that children with intellectual disabilities should have the same rights as children without intellectual disabilities.

Before starting, I will need to determine the legal limits or roadblocks to offering meaningful sexual health education in Surrey public schools. At this time, it is standard practice to gain permission of the parent before providing formal sexual health education in Special Education programs. In order to actually do this research, I would need to obtain permission from the school board.

Logistical/ practical considerations.

Multicultural Issues.

I naturally will want to incorporate the variety of multicultural perspectives reflected by the diversity within the Surrey school district. Identifying attitudinal differences based on cultural variables will help future researchers have deeper insights into the origin of attitudes and give guidance into more specific and culturally sensitive interventions. Surrey is very diverse and it is problematic to assume that all parents in Surrey are the same. Depending on the cultural background of the parent, I would expect significant differences in attitude. I will have to identify the cultural background of each parent interviewed. Even so, it will be impossible to do enough interviews to adequately represent the diversity of Surrey. Therefore, this will be an acknowledged limitation of the research proposal.

Number of Participants.

The ideal number of interview participants is important to consider. As this research is not quantitative in nature, the number of participants can be relatively small. However, I will want to interview enough people to ensure, I have some information about each age group (Grade 8-12) and each gender.

Individual or group interview.

Mothers and fathers will be interviewed separately. Given that one participant may dominate the discussion, I would interview each person separately. It might be interesting to analyze different responses of couples. It will be also important to note any significant different attitudes of mothers and fathers. It will also be important to identify differences parents of boys and parents of girls.

Location.

Ideally, interviews will take place in a comfortable, private off site area. The volunteer's home might be acceptable if the child is not home. Participants will hopefully reveal some very personal feelings; it is important that they feel comfortable and unchallenged.

Delimitations

Certain protocols will be implemented to address possible bias issues. Volunteer parents will likely have different attitudes than parents who do not wish to participate. Obviously, I won't be able to interview non volunteers. This is a limitation to the validity and reliability of the research. This will have to be acknowledged.

Reliability and Validity

Nahid Golafshani helps researchers consider the meaning of reliability and validity in qualitative research (2003).

Reliability and validity are conceptualized as trustworthiness, rigor and quality in qualitative paradigm. It is also through this association that the way to achieve validity and reliability of a research get affected from the qualitative researchers' perspectives which are to eliminate bias and increase the researcher's truthfulness of a proposition about some social phenomenon. (p 604)

Therefore, in order to make my research reliable and valid, I will need to demonstrate trustworthiness, rigor and quality in my research. To me the only way to do this is through

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complete transparency of process. Some ways to demonstrate transparency is through excellent record keeping, a clear justification for choices and sharing interpretations with other professionals, when appropriate.

As a BASES teacher, I exist as a subjective participant in the research. I have no personal involvement with people with id, but I have worked for over 15 years in the field of Special education and I have naturally developed my own biases. I want to see full sexual health education in schools which is supported by parents who want to help their children develop socially appropriate and fulfilling lives that include opportunities to express one's sexual nature. In my time as a BASES teacher I have made many personal observations of obstacles that teenager's face. I have seen many young adults attempt to express sexual feelings in inappropriate ways because they didn't the right way to do something. Many of the students who have graduated from my school are not receiving full social experiences, and therefore, feel lonely and isolated.

A description of the instruments used and reasons for choosing them.

The instruments used for the research will be very minimal. First, I will want an audio recording device with enough storage to have the many hours of interviews. The audio device will be used to create accurate transcripts. I also hope to make the interview as informal as possible, I will want do as little note taking during the interview as possible.

Second, I will ask participants to fill out a form asking for specific demographic information. The form will help me tease out certain themes. For example, do attitudes differ based on age of parents? Do attitudes differ based on cultural or religious background?

Limitations or possible weaknesses of the research design or findings.

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I feel that this research design will have practical usage for educational professionals in the Greater Vancouver area. However, the research may have reduced relevance the older this study gets. Attitudes can be surprisingly temporary and fleeting. Also, the relevance of the study decreases the farther one is away from Surrey.

As this research would be the first formal research by myself, it, inevitably, would be susceptible to mistakes in design and execution that a more experienced researcher would not make. For example, this type of interview based research is very susceptible to the interviewer unknowingly guiding the interview into pre-ordained themes. It is also possible to let earlier interviews influence the way future interviews progress. It will require a skilled and self-reflective researcher to successfully execute the research.

Assumptions that are present about the research or research subjects.

All researcher enter into research with some assumptions. This is only natural because researchers probably have already done lots of investigation of the issues and have developed a keen interest in the subject. Researchers may also have political biases and have specific social goals for their research.

First, one assumption that I will have is that parents are dealing with above average stress in their life. The extra support needs of their child may put financial, social and emotional stress on parents. The knowledge that their child will require specific supports throughout life may also cause significant distress in parents. Finally, I am aware that many parents still feel guilty about their children's condition. I don't think I would assume that all parents feel guilty, but I would be attuned to that attitude and would be looking for evidence of guilt. I would have to make sure that these biases do not improperly affect the results of the study.

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Second, I will be inclined to assume a prejudice in the parents for safety over risk taking. As a result, I will expect to find evidence for restrictive policies or procedures in the home. Typical freedoms given to non-disabled children may not be afforded to children with id. When this happens, I am likely to assume this is because of parental bias towards safety.

Chapter 4

Summary

Chapter 1

In Chapter 1, I outlined a general problem that people with intellectual disabilities face in their lives. Specifically, sexual rights and freedoms are often denied, either intentionally or unintentionally, to people with id. Granted, there has been a blossoming of support for and defense of people with id over the last 40 years. Inclusive education is a legally sanctioned right for all. Institutionalization is a feared and despised part of our history. There has never been such visibility of people with id in mainstream society.

However, many adults with id have desires to get married, have children and engage in sexual activity in the same way as non-disabled people and they are not able to fulfill these desires. It is not oppressive laws that are thwarting people with id. I posit that it is cultural norms and expectations that are thwarting people with id.

One group of people who have the potential to hinder sexual identity formation and expression of people with id is parents of people with id. In Chapter 1, I gave myself the task of determining the attitudes and beliefs that parents may have that hinder the rights of sexual expression for people with id.

Chapter 2

Through a review of existing peer reviewed studies, I was able to identify 5 key thematic topics that reveal the plethora of harmful attitudes parents often have towards their children with id. The overall finding was not that parents feel their children do not deserve sexual freedom. Rather, parents really do want their children to be happy, but the fear they feel causes them to overprotect their children from perceived threats. Some parents fear the potential for sexual

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abuse and exploitation. Some parents think that sexual education may actually promote unsafe sexual exploration. As a result of these fears, some parents overprotect their children and shield them from normal and healthy sexual experiences.

Chapter 3

In Chapter 3, I proposed a qualitative interview-based research study designed to find more practical information about the attitudes of parents of children with id in Surrey, B.C. I designed a study that would provide educational professionals with insight into the attitudes and beliefs of parents living in Surrey, B.C with children attending public high schools.

Although I did not actually conduct the study, I think this study would be very helpful for educational professionals who want to develop the most effective sexual health education programs for young people with id. I hope that this study will promote understanding and communication between the professional and family supporters of people with id.

Implications:

This capstone project has shown me that the effort to fully include people with id in society is not complete. Advocates need to continue the struggle and fight for the rights and freedoms of people with id. For educational professionals, I can think of three specific implications of this study.

First, Individual Education Plan (IEP) meetings with parents and Special Education teachers should include a discussion of sexual health. Sexual health is a very important social domain that should be addressed in every IEP for children with intellectual disabilities. Parent-teacher meetings are excellent formal opportunities to discuss a sensitive topic in a professional,

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yet caring and personalized manner. It is also a great way to give voice to parents who may feel excluded from the educational process.

Secondly, if Special Education teachers and Counsellors need to engage in conversation with parents about sexuality, it becomes very important that there are professional development opportunities for Special Education teachers in Sexual Health readily available. Not only do Special Education teachers, counsellors and administration need to be aware of the content of Sexual Health curriculum, they need to be trained on how to communicate with parents about such sensitive topics. In my experience, I have met many teachers who are afraid to talk about sexuality with students with intellectual disabilities and terrified of talking to parents. If regular training and support is offered by Professional organizations, then teachers may feel more comfortable dealing with this important educational need of students.

Finally, Sexual Health Education programs need to be developed with an up-to-date understanding of parental fears and concerns. I think this study has shown how significant an influence parents are on the sexual development of children with id. Parents can be either powerful supports or impediments to their children. No sexual health curriculum can be effective without parental support.

Conclusions:

A capstone project requires a commitment of much time and energy. For this effort, the reader and the writer hope to be rewarded with a greater sense of clarity and purpose in regard to the problem identified and the questions under investigation.

The first conclusion I have come is that harmful parental attitudes are generated from fear and ignorance. Generally speaking, parents want their children to have happy and full lives,

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even in the realm of sexuality. However, fear of abuse and exploitation can distort the efforts of parents to support their children. Also, ignorance about the effectiveness of sexual health education has paralyzed some parents. Many parents feel that sexual health education is either useless or harmful to their children. The two clichés, “ignorance is bliss” and “a little knowledge is a dangerous thing” come to mind when trying to understand the source of negative parental attitudes. Educational professionals need to combat this level of ignorance and prove that knowledge is power for people with id and leads to greater safety and happiness.

A second conclusion I have come to is many parents feel desperately alone and unsupported by the professionals. The responsibility of raising a child with id can be overwhelming. However, it is a fact that parents are expected to stoically and competently raise their children. Greater efforts have to be made to bridge the gap between parent and professional. As a professional, the only way to make progress in this issue is present ourselves in an honoring, respectful and co-conspiratorial manner. Professionals do have much to offer, but it will not be heard if we talk down to parents and claim to be “The Expert”.

The final conclusion I can share is that there is much evidence to feel optimistic and hopeful for people with id. Although this capstone focused on potentially harmful attitudes, through my readings and my experience in Special Education, I have seen evidence of caring, dedicated and educated parents who are supporting children in innovative and progressive ways.

Recommendations

The research proposal from Chapter 3, if completed, will provide a temporary insight into the attitudes of a particular group at a particular time. This will be useful, but attitudes typically change and evolve. Therefore, it will be important for researchers to continue tracking attitudes

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into the future. It is important to track trends over time, because trends give insight into the effectiveness of interventions.

If we accept the important role parents have in delivering sexual health education to their children, we also have to offer meaningful educational training to parents. We can't expect parents to know everything and be prepared to teach their children complex things without any educational support. Sexual health professionals need to offer their knowledge and experience to parents who seek knowledge and guidance. I recommend that the Educational and Health Care systems work together to offer formal and systematic educational courses for parents about the sexual health of children with id.

Finally, I recommend that schools continue to make efforts to include students with id in formal school events like dances and Senior Formals. These are events where all children practice sexual rituals in safe and supportive environments. Children with id definitely need these structured social events as much or more than all other students. From experience, I know that facilitating the inclusion of children with id in extracurricular events can be challenging. However, I can also say the benefits are huge, and I will continue to help my students participate as much as possible in these events.

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